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Citation for published version:

Clarke, CL, Keady, J, Wilkinson, H, Gibb, CE, Luce, A, Cook, A & Williams, L 2010, 'Dementia and Risk: Contested Territories of Everyday Life', *Journal of Nursing and Healthcare of Chronic Illness*, vol. 2, no. 2, pp. 102-112. <https://doi.org/10.1111/j.1752-9824.2010.01040.x>

Digital Object Identifier (DOI):

[10.1111/j.1752-9824.2010.01040.x](https://doi.org/10.1111/j.1752-9824.2010.01040.x)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

Journal of Nursing and Healthcare of Chronic Illness

Publisher Rights Statement:

© Clarke, C. L., Keady, J., Wilkinson, H., Gibb, C. E., Luce, A., Cook, A., & Williams, L. (2010). Dementia and Risk: Contested Territories of Everyday Life. *Journal of Nursing and Healthcare of Chronic Illness*, 2(2), 102-112doi: 10.1111/j.1752-9824.2010.01040.x

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Dementia and Risk: contested territories of everyday life

Abstract

Background

This paper addresses a gap in the literature by embedding constructions of risk within everyday events and social contexts, and communicates such constructions through the voices of people with dementia, carers and practitioners.

Aims and Method

The project aimed to understand the construction of risk in dementia care from the perspective of the person with dementia, family carers and practitioners with the intention of developing negotiated partnerships in risk management. One aspect of the project involved data collection from 55 people with dementia, and their nominated carer and practitioner.

Conclusions

Five ‘contested territories’ of everyday living with dementia are outlined in this paper: friendships, smoking, going out, domestic arrangements, and occupation and activity. These contested territories are purposeful and allow for sense making, maintenance of self, claiming and relinquishing decision making, and creating purpose(lessness) in people’s lives.

Relevance to Clinical Practice

Assessing and managing risk in a way that respects the dynamics and purposes of contested territories will support care that is person centred, and moreover respectful of the relationships that contribute to maintaining the individual's sense of self and purpose.

Key Words

Everyday life, risk, dementia, carer, symbolic interactionism, contested territories

Background

There is a world-wide increase in the prevalence of people experiencing dementia (Wino *et al.* 2006). In the United Kingdom (UK), the Alzheimer's Society (2007) have suggested that the numbers of people with dementia will rise from 700,000 in 2007 to 940,110 by 2121, an increase of 38 per cent. Such a rise will undoubtedly place additional demands on health and social care agencies, a demand that will only increase as the policy imperative of earlier detection and diagnosis of dementia comes to fruition (National Audit Office, 2007; Department of Health, 2008).

Within the competing discourses and constructions of dementia, the biomedical approach has led to an emphasis on modifying the course of dementia through processes such as diagnosis, assessment and treatment (Hughes *et al.*, 1982; Jane-Llopis and Gabilondo, 2008). Conversely, the experience of living with a dementia has been postulated as being socially constructed in that personal meanings and compensatory coping adjustments will be ascribed by the individual (and family) to make sense of a changing reality. One major proponent of this approach in dementia care was Kitwood (1997) who defined the construct of personhood as a 'standing or status bestowed upon one human being, by others, in the context of a relationship and social being' (p.8). This aspect of dementia as being in relationship with other people was advanced further by Harding and Palfrey (1997). An increasing body of research has explored the experiences of living with a dementia, whether with the diagnosis or as a carer, and studies have progressed from the 1980's and 90's focus on the burdens of caring to research which focuses more on the interrelationship underpinning care

giving and receiving (for example, the phenomenological studies of Gates, 2000, and Todres and Galvin, 2006), and more recently by Nolan *et al.* (2008) where these interrelationships become the focal point for understanding the dynamics of living with dementia.

This shift in focus to the ways in which people themselves live with dementia has heralded an interest in day-to-day experiences. A diagnosis of dementia introduces an unfamiliar element into a familiar home, which is otherwise associated with notions of being a non-threatening environment (Kontos 1998), habitual routines and a place to be free from surveillance (Finch and Hayes 1994). Askham *et al.* (2007) describe how life for a person with dementia living at home is ‘in constant danger of slipping towards the practices and life of a total institution’ (with attendant implications for routinisation, surveillance and mortification of the self) yet Goffman (1961) argued that institutional care and family care could not share these characteristics. Galvin *et al.* (2005) describe a single case study in a paper co-written with a spouse carer of someone with dementia, which identifies the ‘intimate’ carer as a mediator between the private experiences of someone with dementia and the public nature of health and social care systems.

In a major review of research, Mitchell and Glendinning (2007) explore the relationship between risk and a ‘normal’ life, and highlight the differing assumption of family carers and practitioners which inform care. Risk theories provide some

theoretical explanation for the diverse perspectives of people with dementia, family carers and practitioners (e.g. Clarke 2000; Clarke and Heyman 1998). Risk construction, assessment and management are embedded in policy and professional and lay practice, very often implicitly. Despite the limited policy guidance on risk management in dementia care (Department of Health, 2007, omit reference to dementia care for example), it is seen as central to professional practice (Manthorpe *et al.* 1995; Alaszewski *et al.* 1998; Heyman 1998).

This paper attempts to bridge a gap in the literature by embedding constructions of risk within everyday events and social contexts, and communicates such constructions through the voices and language of people with dementia, carers and practitioners.

Study Design and Methods

Aims and Design

The project aimed to understand the variability of the construction of risk in dementia care from the perspective of the person with dementia, family carers and practitioners with the intention of developing negotiated partnerships in risk management.

Data collection included an organisational survey of current risk management (reported in Clarke *et al.* 2004 and Clarke *et al.* 2009) and interviews with 55 people with dementia and nominated family carers and practitioners (see also Keady *et al.* in print). This fieldwork was located within three project sites: North-east England; North Wales; and South-east Scotland, and was conducted in a number of care

environments, including community based and those living in a care home. The study received Multi-Research Ethics Committee approval in January 2003 (ref: MREC/2/3/74).

This paper focuses on the interview data set, drawing on the experiences of four people with dementia (Margaret, Mary Jack and Martin) to explore their experiences of living with dementia, along with their carers and nominated practitioners, to illustrate the everyday construction and meaning of risk.

The study draws on symbolic interactionism as a methodological framework to guide data collection, analysis and subsequent reporting (Blumer, 1969). According to Blumer (1969 p.3) symbolic interactionism rests upon three premises, namely: i) that human beings act towards things on the basis of the meaning that things have for them; ii) that the meaning of such things derives from the social interaction one has with one's fellows; and iii) that these meanings are handled in, and modified through, an interpretative process. Symbolic interactionism views meanings as social products, as creations that are formed in and through the defining activities of people as they interact.

Sampling and Data Collection

The sample of people with dementia were identified as a result of their access to statutory services and were selected purposefully to ensure a range of residential arrangements (living in own home; accessing some day or respite care services; living

in a care home). People whose practitioner felt did not have the capacity to provide informed consent to participate in the research were excluded.

Each person with dementia was invited to participate in up to two interviews, in recognition of the importance of a trusting relationship in interview data collection and the possible fatigue of people (Clarke and Keady 2001). This enabled reflection upon the nature, scope and direction of the first interview and clarification of any points of discussion and/or to seek new pathways for exploration and allowed the research team to consider the consistency of the storyline between the first and second interviews and to probe any change in this. Each person with dementia was invited to nominate a family carer and practitioner to be invited to be interviewed too. All interviews took place in a venue of the interviewee's choice. The data was tape-recorded and transcribed verbatim.

Data Analysis

All interviews were transcribed and subjected to numerous reviews by members of the research team. These reviews built cumulatively from identifying discrete open codes to an analysis of the meanings of risk embedded within the life situation of participants. Following this approach and based on the triadic nature of data collection (with data from people with dementia, family carers and practitioners), analysis revealed a number of risk dimensions which we refer to here as 'contested territories' of everyday living with risk, their symbolic meanings and practical manifestations. The focus of the territory which is contested varies between people, and it is the

nature and purpose of the territory as a place that is contested which is of particular relevance for this study.

Five of these contested territories are described in the following section, with no hierarchy of importance intended as each differs in significance for each person: friendships, smoking, going out, domestic arrangements, and occupation and activity. These are described in relation to the lives of four of the participants in the study (all names used are pseudonyms). In brief:

- Margaret lives on her own in sheltered accommodation. She is in her early 60's and has two children. Margaret knows she has had dementia for about 3 years and has other mental and physical healthcare difficulties. Margaret nominated her daughter Sarah and her Occupational Therapist to participate in the study.
- Martin lives with his wife Jane in a very remote rural area. Martin is in his early 80's and otherwise well, although Jane has some physical health difficulties. Martin nominated Jane and his community practitioner to participate in the study.
- Jack lives with his wife Kath in their own home and has day care each week. Jack is in his late 70's and also has other mental and physical healthcare difficulties. Jack nominated Kath and his Community Psychiatric Nurse to participate in the study.

- Mary lives with her partner Peter in their own home and attended a hospital-based day centre. Mary nominated Peter and one of the day centre staff to participate in the study.

Findings – Contested Territories of Everyday Life

Friendship

Mary used the friendships in her life to achieve two things. Firstly, to relate to people with similar experiences as a way of making sense of her position (as also illustrated in relation to smoking below): *‘we can all have a laugh together about the things that we’ve all done, you know, and it seems to lift the load’ (Mary)*. This was recognised too by her practitioner and by her partner Peter: *‘so they are all in the same boat and she realises she is not alone anymore’*.

Secondly, friendship enables Mary to maintain a sense of self and identity: *‘I still see my friends and I enjoy going out with them. I feel human after that, when I have actually been out with friends’*. In particular, Mary draws a contrast between being *‘out with the girls’* and being out with Peter when *‘it is always “Now don’t do this, or don’t do that”..or “no..you’ll not like that”’*. None-the-less, Mary recognises her dependence on her friends when they are out and its impact on their time together, as in the following quote.

I am not allowed to go out now unless I have one of my family with me.

Whereas before I could go and ring up one of my friends. And I can understand that they'll say 'Oh, I've got something planned'. It's because, although we have been very good friends for a long time, is that they don't want to have to take the risk of taking me out on their own. And I agree with them. Because if anything were to happen to me they would feel it was their fault. Well it isn't, it's me! (Mary)

In this quote, Mary illustrated the role that others play in another of the other key contested territories, that of 'getting out'. Getting out is important to her, but is something she describes as being 'not allowed' to do alone, and that is problematic for her friends. Martin recognised too that, as his dementia progressed, when he went fishing his friend was 'always on the lookout for me'.

Martin often felt tongue-tied in conversations, which frustrated him in his friendships.

I think most people I know understand, and will wait for it to come out or I say 'oh forget it!' (laughs). Jane's (his wife) got to help me with a lot of words of course, but I think that's the worst, because it upsets you, you're not one of the boys again, at all you see. Whereas you should be talking to people about the old days and telling them all about it, I can't do it. (Martin).

However, Jane is starting to feel that their friends are less inclined to meet up, as in the quote below, and is protective of Martin being exposed as unable to manage larger public events with friends.

I'm beginning to feel, we have quite a lot of lovely friends and relatives, and there's the odd one or two that ... an excuse not to stop long because he takes so long to tell people his stories and he gets all confused that I think some people get a little bit bored or intolerant of it. (Jane)

One of the other people with dementia, Margaret, identifies the need for a balance in being with friends and relatives: *'a friend comes over once a week, we go out for a meal, that's enough. I don't want to be with people all the time, I like to be on my own'*. Margaret has experienced a contraction of her friendships as a result of her own withdrawal from activities (including voluntary work and as a counsellor) and as friends have died, resulting in an impoverished experience for herself.

I miss sort of stimulating conversation ... and I miss meeting interesting people and all, I miss that I must say, I don't very often meet interesting people now. ... when I was in [voluntary work] ... there was quite a lot of interesting women, and when I used to go to counselling I had a few interesting friends

and they've all gone. ... I've had a few friends died as well, close friends have died. ... I talk to people on the net, which has been a life saver really.

(Margaret)

Margaret's friends were seen by her daughter Sarah, the main carer, as an important support network which together with service involvement '*makes it easier for both of us and then our relationship is less fraught*' (Sarah). Both Sarah and Margaret's nominated practitioner wish she had more confidence to be involved with her friends and join in social activities.

Smoking

For Mary the day-to-day event of smoking was a core narrative in both of her interviews. It provided simultaneously an explanation for her stroke-related dementia and was, paradoxically, also a source of comfort.

I feel that man upstairs (God) has played a rotten joke on me by giving me this disease I've got and I can't get rid of. Other people would say 'well you shouldn't smoke', but that's the only pleasure I've got, it calms me down.

(Mary)

Smoking was also a key feature of Mary's social network activities and through these she formed a process of making sense of her current situation.

(Smoking is) one of the reasons why I come to places like this (day centre). It gives me other female company and we can have a laugh, we can discuss things. Sometimes I make them laugh. I come out with some daft things. ... Yes, we do talk you know about, there's no restriction. There's about four of us like to go outside for a cigarette but there's a special place now where we can sit indoors. I can have a cigarette and discuss things. When you hear some of the tales other people tell you, you think to yourself straightaway 'oh, well there's not just me'. (Mary)

Moreover, smoking was a territory of her life that was highly contested by her partner Peter, something that Mary was well aware of and she had adapted her behaviour to avoid his censure.

He gets on at me, so I normally do it (smoking) when he goes shopping or I might at night when he might have gone out. (Mary)

Peter was anxious to explain in his interview that he not only regarded smoking as one of the causes of her stroke but that he had reason to be concerned for her welfare from continuing to smoke:

She's burning her jumpers, because she has jumpers with holes in you know.

Dressing gown, full of holes here. I says 'what happened?' Shall I get it?

[Peter leaves the room to get Mary's dressing gown] You see the way she has left these burns in it?

(Interviewer – 'Oh dear, yeah. All around the back as well')

That's what I worry about. And that's the risk that when I go out that she sets fire to this place. (Peter)

In seeking to manage this contested area of Mary's life, Peter was becoming increasingly vigilant and reluctant to leave her alone for more than half an hour. Interestingly, in terms of the practitioner interview, smoking did not appear in the analysis of perceived and assessed risk factors.

Going Out

Going out, whether on foot or by car, was invariably a territory that was contested and which raised many challenges for people with dementia and those who cared for them. For example, as well as smoking (described above), going out was another

activity disputed between Mary and Peter and which she perceived as necessary to retaining her identity.

I miss doing things most women do, go shopping. ... Now and again I sneak out... I don't tell Peter because he'll go off it. He doesn't like me going out unless there was someone with me. I mean everybody in the street knows me, even in the shop, but 'if you want something you tell me and I'll bring it up' and I think 'well, I'm sitting here doing nothing, I could be around and back' but he'll not have it. ... I think he's frightened in case I take a wrong turning and I don't know where I am. But I cannot possibly take a wrong turning where we live. 'What do you want to go in there? You should have told me I would have brought it in' and I think 'Oh man, give it a rest'. (Mary)

This contested activity of going out was recognised by Mary's practitioner:

Going out with her partner was difficult because she can't walk very far... she hasn't got the muscle strength. So I felt that her choices were limited and most of the choices in what she wanted were being made by Peter, her partner. ... so we talked about how having a wheelchair would enable her to maintain her ability'. (Mary's practitioner)

Margaret, like Mary, has mobility difficulties that are not related to dementia.

Margaret, however, is reluctant to go outside her home: *'I don't go out very much, I don't go out at all on my own... I went down to the dentist yesterday, but I got a taxi there and back and I don't like it, I hate it, I feel a bit vulnerable, but my sister takes us and my daughter takes us...'*. One of the reasons that Margaret dislikes going out is that she hates relying on other people: *'I hate depending on other people, and you're asking people to do things for you'*.

Having experienced her own mother with dementia 'wandering', Margaret joked: *'at least I cannot wander very far because I've not got the mobility (laughs)'*. Margaret's practitioner feels that she is *'more cautious than I'd like her to be. ... go out a little bit more. She's very fearful about going out by herself now'*. Margaret's daughter, Sarah, however, recognises her mother's reluctance to go out as a concern which she links to the contested territory of friendship: *'she just refuses to go anywhere without anybody so she's very isolated'*.

The part that going out plays in maintaining friendships was also experienced by Jack who enjoyed amateur dramatics and had hoped to transport his fellow actors.

As far as the driving was concerned, I lost my orientation. I kept getting lost in other words. So I decided and I was advised, by that time, my medical condition was more obvious or evident, so I was told I shouldn't drive. ... I

was on the point of getting a minibus to take people... but I just had to give that up and a lot of my colleagues, if you could call them that, were disappointed that I had to give all this up. (Jack)

Jack also experienced some attention by staff in the day centre to his mobility and movements, which he resented a little.

They're inclined to be a little bit fussy in the centre that I go to. If somebody doesn't stick to the path sort of thing. I mean with the best of intentions, they are anxious that you don't do anything by which you'll injure yourself. When I first went there I was a bit piqued because I didn't think I was that bad...

(Interviewer – 'So what kind of things do they discourage you from doing there?')

Well stepping out of the building. I wanted to get some fresh air. Anyway, they found somewhere I could sit, which solved that problem. ... oh they're very exact about the way I walk, the way I use my walker because I'm inclined to cross my hands or something silly like that or just put it one-handed and they stop me doing that but they do it in the best, in a good humoured way. (Jack)

For Martin, driving remained an important part of his life since he and his wife lived in a very remote area without access to shops or other facilities without driving.

Although his wife Jane drives, she felt that to stop driving would be very hard for him: *'Oh I think it would kill him if they [took away] the driving! Not kill him but I think that would be terrible! I think he'd deteriorate if he couldn't drive'* (Jane). The difficulties of this were recognised by Martin's practitioner.

I think she's quite anxious about what happens if he stops driving as well, because they live in an isolated place...he goes up the M6 doesn't he (laughter)...well Lancashire, up the M6, and the M53 or whatever, must be horrific if you've got even a slight memory problem, its bad enough when you haven't...they've always done it. (Martin's Practitioner)

Domestic Arrangements

It was over domestic arrangements as a contested territory that there appeared to be most disputes over relinquishing (former) responsibilities and that demonstrated ways in which people with dementia strove to retain their independence and sense of themselves. Mary illustrates this in the following descriptions of how she and Peter have renegotiated their roles in the home, and the impact of this on her sense of autonomy. She describes Peter as having to *'put the "no go" face on'* when he steps in to stop her doing something. As Mary went on to explain:

I'm not allowed to do anything in the house. I've always had someone who comes to do my housework. It's not because I'm lazy, it's because I haven't got the power to do it. If I did try to do it by myself well I'd make a, excuse the language, a hell of a mess. ... Sometimes, the odd times when I've washed up, because Peter does that, I've managed the washing, and dried them, but I put them back all in the wrong places. So he's had to sort that out. 'Will you please leave that alone', and I feel as though I'm not wanted. (Mary)

(Interviewer – Before you were ill were you the one who made the decisions...is that a big change?)

Yeah. I decided when we went food shopping and what we would have for a meal, we could eat out or we could come home, anything like that, or if there was anyone in the family that wasn't very well it was me who said 'You'll have to get some flowers and go and visit them. We will have to'. But now he does all of the things like that. (Mary)

Peter concurs with these changes in their domestic roles: *'I took Mary over and I'm doing all her thinking now'* (Peter). Although doing the majority of the domestic activities now, Peter describes how *'the problem now is watching, wondering what she's doing now you know, mislaying things'* (Peter). Mary's practitioner described how, through attendance at the day centre, Mary now had a renewed interest in her

home, was choosing how to redecorate it, and had a wider range of things to converse with Peter about.

So she is decision making. That was our greatest fear when she came here was that Peter was taking over her decision making. And that's the last straw if she is someone with a strong personality where someone is not allowing me to make my decisions, it makes you feel childish. (Mary's practitioner)

Margaret's daughter Sarah was also faced with making decisions about when to step in to help her mother: *'I worry when she cleans the fish tank out because it's great big buckets of water... but at the same time, they're part of normal things to do, so you don't want to say "oh no"'*. Similarly, when Margaret's practitioner was asked what was seen to be the most important things for Margaret, she replied: *'being able to do her own thing, when she wants, how she wants, not somebody coming in and managing her, her life'*.

Margaret has also relinquished domestic activities which she had previously found satisfying and fulfilling: *'I've stopped cooking, I used to cook for the family and I can't do that anymore because I've scalded myself so many times ... I forget to put the gas off, I turn the wrong lever and I've set light to a couple of tea towels'*.

I used to love cooking, I really did. I enjoyed it, baking and making meals and things like that, I was sort of known for all my cooking. Now I can't, I live out of packets. I'm slowly getting rid of things out of the cupboard...its hard to give the things up, the cupboard's still full of cooking things. (Margaret)

Jack had also relinquished cooking activities: *'he doesn't do any of that now ... I think it was just something that happened. He just wasn't able to do it so it just wasn't done anymore'* (Jack's wife Kath). As a result Jack's practitioner recognised that he was vulnerable to his wife's poor health and possible inability to look after Jack.

Margaret also highlighted her diminishing financial control (*'I forget to pay'*) but her reluctance to stop having access to credit: *'I don't feel I'm ready to give [credit card] up yet'*. Unlike Margaret, Jack's diminishing financial control had resulted in debt and he no longer managed the domestic finances: *'I mean when they discovered (the debt) it was quite a shock to the system'* (Kath).

One aspect of domestic arrangements is to deal with medical appointments, and at times relatives described needing to advocate for the person with dementia and to accompany them on medical appointments. Margaret's daughter Sarah described how her mother *'likes someone to fight her corner sometimes, and then it irritates her that people have to fight her corner'*.

In Martin's life, he had relinquished different aspects, including the role he had assumed previously of organising holidays for a group of friends, and day-to-day communication and finances: *'I used to do all the work...but its all, had to turn it over to her (Jane, his wife) you see – who's really good, I think she's far better than me actually I ever was'* (Martin).

I used to take (relatives and friends on holiday) and I used to hold everything, the kitty and everything and get them on the bus or whatever it was, 'come on, this is it' and that type of thing and everything like that, well that's gone now.
(Martin)

The care that the person with dementia showed for their relative remained strong, and was a particular concern for Martin: *'I'm worried about her (his wife Jane) more than anything, that she's been very poorly, because this is the second time round you know, and I don't want her to do things, I'd rather let the bloody house fall to pieces...'*.

Martin's practitioner described how Jane keeps him involved and active in household matters: *'I think he does a lot for her, and I think she does bully him into doing it as well. She doesn't let him sit there and she doesn't wait on him hand and foot so he is part of the household as well'*.

Occupation and Activity

Margaret is a former nurse, and now at 60 years old, had spent time in several roles since leaving nursing, each of which she has had a leave as her health has deteriorated. As a result she has had to adapt to frequent changes of activity, and with each change has had to address feeling unable to continue. At present, Margaret is enjoying making cards which are sold at craft fairs. Each of these changes address the need for Margaret to have a sense of purpose in her life. She describes how she has *'just sort of substituted things'*.

(when I left nursing) it was horrible for a little while and I felt useless ...started to do voluntary work ... and then did a counselling diploma and did voluntary counselling for up to about three years ... so I was quite busy...when I had to stop I felt useless.

(Interviewer – 'What led to you stopping the counselling?')

Well, because I couldn't remember people's stories you know, I got mixed up with them and I mean its quite stressful counselling... then I set up a library (for a woman's health group), do the books and things, but then that even got, because I got mixed up I didn't know where things were, I didn't know which books I'd done and which I hadn't and I got my system mixed up so I gave that up...I felt a bit down again, useless... (Margaret)

Her daughter Sarah associates these occupation changes with constant changes in her mother's social networks and friendships too. Although not mentioned by Margaret herself, Sarah does leave her children with Margaret regularly: *'I leave her grandchildren with her because one, it alleviates the fact that she feels useless. You know, she's now, she's great with the kids. Except (one of her children aged 8 years) who is going through that yak yak yak age and it does her head in...'* (Sarah).

Discussion

The findings of this study raise points for discussion in three key areas: firstly, the role of everyday life in the experience of dementia; secondly, some purposes of contested territories are proposed; thirdly, some aspects of risk theory are drawn on to provide some explanation for the experiences of people with dementia, their family carers and practitioners.

Everyday Life and Dementia

Attention to everyday life as a place that is simultaneously normal and familiar and yet also a place of tension and diverse perspective is rooted in Bourdieu's (1977) work on the theory of practice. Mirroring Blumer's (1969) description of the interpretive processes in symbolic interactionism, Bourdieu explains how, through a theory of practice, an external world is internalised by individuals and in turn reflects back that external world. Each individual produces and reproduces meaning, yet

actions and words may result from unconscious assumptions and internalisation of external social dynamics. Individual experiences collate and self-reinforce to form 'habitus' of social expectation with attendant structuring and structured structures.

In the study described in this paper, this plays out in two ways:

1. The everyday life of someone with dementia becomes an unstable structure with competing habitus as the expectations of adult independence and established family life are confronted with the expectations of dementia as a disease and psychosocial entity. For example, Margaret describes how she has stopped cooking because of her forgetfulness yet it is an activity she enjoys and she is reluctant to discard the now unused food and cooking equipment.
2. Each member of the triad of person with dementia, family carer and practitioner seeks to form a bridge into each others practice, recognising their need for each other but also their differences. For example, Mary, her partner Peter and her nominated practitioner all raised concern about how extensive Mary's own decision making should be. This is, therefore, a little different to the 'liminal' (bridge-making) role described by Galvin *et al.* (2005) which resides only with the family carer.

The Purposes of Contested Territories

The practices of 'everyday life' are a means of conceptualising the fluid way in which people live with a dementia. There are four core dimensions which arise from the

contested territories of everyday life identified in this study, and which render the territory as a place of purpose in the fluidity of lives which are being constantly redefined by the introduction of dementia into peoples' lives.

1. *Sense making.* One purpose of a contested territory is to provide an explanation for events, such as we are witness to Mary's reference to smoking as both the cause of her stroke and her comfort in managing its consequences. It is through sense-making processes that people rationalise their engagement with (potentially) health-harming activities (Dervin 1992). In this way, Mary rationalises that to maintain her quality of life, smoking and going to the shops alone are actions which make sense. Margaret, however, made sense of having stopped cooking as she felt unsafe doing so, despite encouragement from others to maintain this interest.
2. *Maintaining self.* A second purpose of a contested territory is to maintain a sense of self. As dementia (or at least its social consequences) threatens an individual's awareness of themselves and their ability to express themselves, so the person with dementia retaliates by accessing activities which reinforce their identity. For example, Mary likes to maintain 'doing things most women do', and Martin regretted being unable to continue to organise holidays with his friends. This process may or may not be supported by a family carer or a practitioner: Jane, for example, was described as working to ensure that her husband Martin stayed involved in household activities. Both Jack and Martin were faced with contemplating stopping driving – but whilst Jack had stopped,

Martin continued to drive and was supported to do so by his wife and practitioners. Crisp (1999) describes people with dementia as engaged in the process of ‘defending, negotiating and reconstructing an identity for themselves’ as they make sense of their diagnosis and their changing relationships with the people around them.

3. *Claiming and relinquishing decision making.* This third purpose of a contested territory is arguably the area of most conflict. It reflects the changing social and family positioning of the person with dementia in which their decision making role is gradually adjusted. At times, decision making was relinquished voluntarily by the person with dementia. At other times, the family carer or indeed the practitioner assumed, or claimed, authority over decision making processes, or sought to influence another’s authority. For example, Mary’s practitioner was concerned about the level of decision making claimed by her partner Peter. Indeed, many people with dementia are vulnerable to disempowerment, through decisions being made for them, and may thus no longer be regarded as autonomous individuals, capable of making decisions for themselves (Parker and Penhale 1998).
4. *Creating purpose(lessness).* In this fourth function of contested territories, the dynamic is used to frame purpose (and purposelessness) in the life of the person with dementia. In one example, Sarah seeks to mitigate her mother Margaret’s difficulty in finding a purpose and activity in her life by emphasising her role as a grandparent.

Contested Territories and the Experience of Risk

The analysis of practices of everyday life described in this study, and their purposes, adds a more fluid critique to living with a dementia than is described by Askham *et al.* (2007). In a study of social relationships when people with dementia are cared for at home by relatives, Askham *et al.* (2007) identify characteristics of Goffman's (1961) defining aspects of custodial care: routinisation, surveillance and mortification of the self. These characteristics were, however, all evident in the present study to varying extents and to various degrees are enforced and mitigated by the practices of the person with dementia, their family carer and their practitioner. Indeed, just as Goffman found, the people with dementia in this study used various tactics in an attempt to maintain their identity – Mary for example, sought opportunities to smoke (despite Peter's attempts of surveillance) and shared her experiences with friends. Walker *et al.* (2006) also identify that family carers of people with dementia adopt a role of supervision and worry that something harmful will happen if they leave their relative alone (however, unlike Bond *et al.* 2002, Walker *et al.* argue that the carers' judgement of the likelihood of harm is reasonable). This present study also supports the work of Mitchell and Glendinning (2007) who, in their research review, identified that risk-taking activities could be undertaken 'covertly' by older people without the knowledge of family and practitioners who were supporting them.

The reflexivity of Bourdieu's theory of practice is resonant with the reflexivity which underpins Giddens' work in risk theory (Taylor-Gooby and Zinn 2006). Morgan (1999) explores the notion of practices further, emphasising their everyday nature, the

interplay between multiple perspectives and interpretations, and their dynamic nature despite there being a regularity and biographical dimension. It is in this dynamic nature of everyday life that this present study illustrates how a person with dementia, their family carer(s) and practitioner(s) variously amplify and attenuate risk constructions, assessment and management (Masuda and Garvin, 2006, present a useful application of the social amplification of risk). The importance of this is highlighted when considering the findings of Bond *et al.* (2002) who describe a diagnosis of dementia as possibly leading to professional judgements about lack of insight which lead to depersonalisation and loss of independence, these being irrespective of the probability of risk. In this present study, we can see that it is carers as well as practitioners who may amplify risk perceptions, and that practitioners are often seeking to attenuate the amplified risk perceptions of family carers and people with dementia. For example, Peter possibly amplifies the risks faced by Mary, and her practitioner attempts to mitigate this and attenuate the perceptions of risk. Similarly, Margaret's practitioner (like her daughter) seeks to attenuate Margaret's assessment of risk and encourages her to leave her home and engage in activities.

The purposeful dynamic of contested territories has implications from dementia care policy and practice. Risk assessments need to consider a wide range of perspectives, and in particular that of the person with dementia. Development work with practitioners, and family carers, can address the role they play in amplifying and attenuating risk. Contested territories can be explicitly assessed as a mechanisms in

which people with dementia make sense of their situation, maintain their sense of self and seek to continually negotiate their decision-making.

Limitations of the study

Several steps were taken in this symbolic interactionist study to maintain the credibility and trustworthiness of the data. This included: repeated interviews with the person with dementia; triangulation of data sources between the person with dementia, family carer and practitioner; and a data analysis process which involved multiple members of the research team. The influence of the research and researchers on the dynamic of everyday life is fully acknowledged. However, there are some limitations to the study which need to be acknowledged. Firstly, although drawn from three countries of the United Kingdom, there was limited cultural diversity among the study participants. It is inappropriate, therefore, to presume that the findings of this study are relevant across a range of cultural backgrounds. Indeed, there is little research into the experiences of caring for older people among minority ethnic groups (Adamson and Donovan 2005). Secondly, the large majority of the participants in the study either lived in residential care environments or with family / friends who cared for them. As such, the study does not explicitly address the position of people who live alone with dementia (indeed, Gilmour *et al.*, 2003, emphasise how few studies do address the needs of these people).

Conclusion

It is in aspects of day-to-day life that living with dementia is experienced. This symbolic interactionist study, drawing on interview data with people with dementia, carers and practitioners, illustrates how aspects of everyday life become places, or territories, in which the place of dementia and the person with dementia are contested. We argue that these contested territories are purposeful, allowing for sense making, for maintenance of self, for claiming and relinquishing decision making, and for creating purpose(lessness) in peoples' lives. It is through these contested territories that the person with dementia, their family carer and their practitioner seek to moderate each others' perceptions of risk and explain and reconcile the changing family dynamics.

Relevance to clinical practice

Assessing and managing risk in a way that respects the dynamics and purposes of contested territories will support care that is person centred, and moreover respectful of the relationships that contribute to maintaining the individual's sense of self and purpose.

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